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Right: Organizations such as the American Society for Deaf Children offer parents critical support, allowing them to share experiences and information.

FOR PARENTS AND CHILDREN

access is key— to curriculum, to services, and to each other

By Jodee S. Crace, Jennifer Ronco, and Tami Hossler

Why do parents seek other parents? They want advice, tips, and/or wisdom; they want to share stories; they want to learn from the experiences of those who have traveled a similar road before them. Sometimes parents bond with each other, and sometimes they form close friendships. Parents want informational and emotional support. They may prefer support that focuses on a specific concern, question, or need. They may also simply want to be a part of a group—for socialization, activities, or workshops. They may prefer to get information directly from others rather than through reading literature or searching online.

Parent-to-parent support is vital for parents of all children, but, of course, it is especially vital for parents who have deaf or hard of hearing children. Without the support of other parents, those with deaf and hard of hearing children can easily feel isolated, confused, and alone. Once they meet each other, however, those same parents feel enriched, both by learning about the experiences of others and by sharing their own.

Access is key—to each other for comfort and meaningful support, to information for the knowledge they need to support their children academically and emotionally, and, above all, to their children's thoughts and feelings. At the American Society for Deaf Children, our goal is to support parents and their children in whatever way they need to gain access. Below are two parents' stories.

Embracing “Deaf” with a Capital D

By Jenny Ronco

Every family's initiation into the world of parenting a deaf child is a unique and defining moment. No matter how events evolve, there is always *that* day, *that* comment, *that* look, *that* doubt, or *that* doctor's appointment in which a rift forms, a divide between what we took for granted before and

Photos courtesy of the American Society for Deaf Children, Jennifer Ronco, and Tami Hossler





what we will take for granted for the rest of our lives. I'm grateful that my transition, a terrifying experience from one side to the other of this great divide, only took 24 hours. When the Deaf community—and the hearing families and professionals within it—offered their support and complete unconditional acceptance of my daughter, my family, and myself, I was ready to accept it. This acceptance granted access to a community I would never have known otherwise. In turn, the Deaf community provided my daughter with access to language, opening the door to clear communication within our family and access to spoken and written English. All these elements empower her to succeed academically and use her communicative flexibility to enrich her life with an array of friends.

Our journey started on a Tuesday in May. First was the telephone call. On the other end was a technician. The information he provided was heavy on strange vocabulary and light on usefulness. I heard that my baby daughter had a bilateral severe to profound sensorineural hearing loss without having any idea what that meant. "She's not deaf, she's bilingual!" was my

knee-jerk response as we blamed our long wait for expressive language on the German/English input we provided at home. It was quite a wave of denial, but I pushed through it enough to make contact that day with the local Deaf and Hard of Hearing (DHH) program in our school district. By lucky timing, I was invited to a district-wide potluck the following evening to celebrate the deaf and hard of hearing seniors who would graduate that June. I went with my family.

At this event, parents shared their stories and the soon-to-be graduates talked about their accomplishments, struggles, and plans. The evening was a mosaic of speech and signs. When we were announced, along with the fact that we had received news of the diagnosis only the day before, everyone in the auditorium stood up and gave us a spontaneous ovation. Every prospective graduate stopped and visited my daughter, who was in her stroller, to sign "hi" and "welcome." Every one of them voiced the same to me.

Following the event, staff from the DHH



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Left: Jenny Ronco and family on the John Muir Trail.

program encouraged us to visit the preschool, which I did that Friday. At the preschool, my daughter was immediately invited to join in though the staff didn't even know our last name. That obstacle was waived aside, and I was informed that the "paperwork would follow." We stayed and played. Dakota, her big brother, and I were sent home with name signs for each child and a stack of books and videos to get us started on signing at home. Our journey into the world of American Sign Language (ASL), hearing aids, and language acquisition started in that colorful and safe classroom. The German I had used with my daughter for the previous 17 months was set aside; *bilingual* in our household took on a whole new meaning—English, ASL, and *access*.

I would easily learn as much on those mats and tiny blue chairs as I learned in my college-level ASL 1 class. I was suddenly teaching a language that I did not know to my children. There was no time to waste. Dakota needed to know that I was her *mom* and she could tell me anything. I needed to learn, too, quickly enough to teach and fluently enough to listen.

Pitfalls of awkwardness, self-doubt, and a feeling of ineptitude were inevitable, but all paled to the reward of communicating with our toddler. Dakota learned to sign "no" in a few

days, and could "talk back" in signs in just over a week. Within a month she figured out that she could get the last word in any argument simply by closing her eyes.

I remember when she tested her boundaries by stepping away from me towards the curb. She rapidly signed "no, no, no" and squeezed her eyes as tightly as she could. Then, hands on her hips, hair shining in the morning sun, and chin jutting out like a little bulldog, she moved away—punctuating her communication with a giggle. She was one satisfied toddler. She had been waiting a year and a half to let me know

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what she thought about some of the rules we had around the house. Now she was doing it.

Today Dakota is 13 years old. She stills says what she thinks, and I feel lucky to watch and listen to her. When sign language classes and parent workshops proved inadequate, I made a big move and got a master's degree in deaf education. Yet I cannot keep up with my daughter. She navigates the hearing/deaf worlds with grace. She is on target with academics and approaches communication with an open-minded persistence that is a sight to behold.

Dakota learns new and abstract information most quickly with ASL, and she articulates her questions and understanding in written and spoken English. She asks for clarification when she needs it, and she tends to take difficult concepts on a "test drive" in ASL and English to see where the connections are strongest, and pursues her questioning from there. Watching these moments makes our family's bilingualism less of a journey and more of a gift.

The Deaf, with a capital D, community and culture had stood and applauded a diagnosis that makes most of the population shake their heads. From the beginning, ASL easily and immediately granted my daughter a voice. Through ASL, she gained access to the wider community and a rigorous academic curriculum. She is empowered with fluid communication skills, ensuring her continued success academically and socially.

When did I find and embrace the Deaf community? The minute I picked up the phone and they gave us access—and embraced us.

Finding the Missing Pieces— Other Parents, Deaf Adults

By Tami Hossler

When we learned our second daughter, Erica, was deaf, we were overwhelmed with questions of what to do. Like most hearing parents, our daughter was the first deaf person we had ever met. While

we went through all the motions of detection and early intervention, we still felt a huge part of the information that would form the equation we needed to help us raise her was missing. What was it that we needed to know?

We didn't know what was missing until it walked directly into our path. For us, the missing pieces were two forms of access: we needed another hearing parent who was going through the same thing, and we needed a deaf adult mentor to give us insight, advice, and support as well as the tools to communicate with our daughter.

Living in a rural area, we finally found access to a preschool designed for deaf and hard of hearing children—an hour and a half away. For the first five years of our daughter's life, we made the trip to that preschool four days a week. That is where we began to meet other hearing parents. It was a great relief to be able to talk to others who were going through the same things we were. Access to people like ourselves enabled us to make some amazing lifelong friends.

Yet, something was still missing. It wasn't until we moved to Indianapolis, so our daughter could attend the Indiana School for the Deaf, that we found the other missing piece. Here we realized that access to and mentorship from parents and professionals who were

themselves deaf was critical. They helped us acquire fluency in ASL. They helped us understand the cultural mores of the Deaf community. They helped us set up our home to be visually accommodating. But most of all, they helped us embrace our daughter; we could understand and appreciate her for the child she was and the person she has become.

Providing our daughter with fluency in language was always our number one priority. We couldn't fathom not being able to communicate with her. This meant that we, her parents, needed to learn the language that was most accessible to her. This language was sign language. From the moment we learned she was deaf, we started learning signs. Unfortunately we didn't have full access to ASL until she attended the Indiana School for the Deaf. Prior to that we tried a variety of signed systems—all of which proved inadequate and frustrated us often. ASL, the language of the Deaf community, enabled us to deepen both our awareness and skills, and therefore increase the access our daughter would need to the community she would call her own, her school curriculum, and to us, her parents.

We learned how important it is for individuals to have a connection to others who use the same language and



live similar experiences. For our daughter, this came through her school and the Deaf community. By attending a school with other children who were deaf, she became connected to deaf and hard of hearing students from across the nation. Later, when she entered Gallaudet University, she connected with deaf and hard of hearing individuals from around the world. Just as important, the access that ASL afforded her to understanding English and the school's curriculum, through reading, exploration, discussion, and discovery, assured her access on par with her hearing peers around the country to the world we live in today.

Erica, now a graduate of Gallaudet University, works at the California School for the Deaf in Riverside and takes courses towards her master's degree. We don't see her as often as we would like, but we know she is happy—in fact, she is loving her life. This, of course, is what most parents want for their children. We could not ask for more.

As we reflect on the path our lives have taken, my husband and I agree: It was us, not our daughter, who needed an intervention. We are thankful to everyone who made our journey together so special, and we continue to work alongside the American Society for Deaf Children, the Deaf community, and other parents, professionals, and deaf individuals to ensure educational equality for deaf and hard of hearing children.



Above: Tami Hossler and her husband with their daughter, Erica.